

Exploring end of life care for South Asian Kidney patients – interviewer reflections

Abstract

The reduction of inequalities in access to quality care has been a central tenet of UK health policy. Ethnic minorities may experience additional inequalities because of language and other cultural barriers. This paper reports interviewer reflections of conducting interviews with South Asian kidney patients about their experiences of end of life care. It explores themes which emerged from the analysis of a focus group held with eight bi-lingual research interviewers. The relevance of these themes to understanding inequalities and access to end of life care is discussed; together with the potential for the research process to contribute to service improvement.

Keywords: end of life care, ethnicity, south asian, interviewer, cultural competency, diversity

Exploring end of life care for South Asian Kidney patients – interviewer reflections

Introduction

Researching access to end of life care necessarily relies on individual data to understand the reality of how care is experienced by patients. A person has access to quality care when it is meaningful and effective (Gulliford et al, 2002) so interviews conducted in the persons preferred language can provide a reliable way of capturing patients' experiences. There is, however, a lack of research which includes ethnic minority groups because of perceived lack of participation and the extra resources required for translation for non-English speakers (Gill & Lloyd, 2009). The inclusion of different population groups is not only vital to healthcare research in parts of the country with ethnically diverse populations and into disease areas where some ethnic groups have greater risk than others such as diabetes and kidney disease (Burden et al, 1992), but because by understanding variation, including similarities and differences within patient populations, services can become more aware, adaptable and effective at delivering quality care to all patients.

Kidney care and end of life

The potential of renal replacement therapy, that is dialysis and transplant, to provide life sustaining treatment raises challenging decisions for patients, their families and care providers when a person approaches the end of life phase (Da Silva Gane, 2014; Kane, 2013). Choosing not to have dialysis is not a 'no treatment' option and what is termed 'conservative management' can relieve many symptoms and maximise the person's health during the remainder of their life (NHS Kidney Care, 2009). The practice guidance and quality standards for National Health Services (NHS) kidney care require patients with established kidney failure to have timely evaluation of their prognosis, information about choices

Commented [A1]: Please consider rephrasing – this sentence is awkward and unclear.

available to them and for those near end of life, a jointly agreed palliative care plan built around their individual needs and preferences (Department of Health, 2005).

Exploring End of Life Care for South Asian Kidney Patients Study

The Exploring End of Life Care for South Asian Kidney patients study focussed on the end of life care delivered to South Asian patients under the care of kidney services at four sites in the United Kingdom (UK). Previous studies have identified a need for end of life care research to include ethnic minorities (Morton et al, 2010), identified the inequalities in kidney outcomes in the disproportionate numbers of South Asian patients with End Stage Kidney Failure (ESKF) and longer waiting times for transplant compared to the White European population (Randhawa, 2012). Better understanding of how to improve access to quality end of life care for South Asian patients with ESKF is important to service providers providing care to diverse populations and led to the development of this project.

Description of the interviewer work conducted for the main study

As part of the Exploring End of Life Care for South Asian Kidney Patients study, research interviewers (the majority of whom were bilingual in South Asian languages, see Table 1) interviewed 16 patients across three research sites: West London, Leicester and Bradford. The interviews took place in the patient's preferred location (the majority at home) and language (English, Urdu, Punjabi, Bengali or Gujarati). Informed consent was taken first and interviews recorded, translated (as necessary by the interviewer) and transcribed into Word documents for analysis. Interviewers received training in conducting research interviews with patients about sensitive issues such as end of life care and the majority were experienced research interviewers. Interviewer training was in the form of three 1 day workshops which

included presentations, role play, translation and discussion with researchers and practitioners who had expertise and experience in this particular area of research.

Insert Table 1 here

Learning from the process: interviewing the interviewers

The aim of this element of the study was to capture learning about conducting research interviews with South Asian patients with ESKF about end of life care by interviewing the interviewers themselves. Interviewers were asked to contribute their reflections on the research through a focus group at the end of the study. Focus groups are a useful method to collect data about individual experiences and to clarify ideas on topics, in this case the individual interview process, which benefit from group interactions and mutual support in expressing thoughts and feelings (Kitzinger, 2006). The findings of the focus group, which are reported here, fed back into the research process to develop further research about end of life kidney care by the University of Bedfordshire and collaborators.

Method

A single focus group was held with 7 interviewers who had conducted the patient interviews for the study. This took place following completion of the project and involved a brief presentation about the research, informed consent to participate, followed by a guided focus group discussion (Finch and Lewis, 2010) covering the following areas: the research process including cultural aspects; the interview including their role in this and in relation to the end of life care context; and suggested improvements for future research based on their perspective and experiences.

The group was facilitated by an experienced researcher in the field of diversity research (GR) supported by a research colleague (MW) who recorded and transcribed the discussion verbatim. The resulting transcript was verified for accuracy and analysed thematically by a third researcher (EW, who was also a participant in the focus group) with oversight and input from GR and MW. EW is an experienced public health researcher with expertise in action research including qualitative methods. The principles detailed in quality standards for conducting and reporting qualitative research helped to guide the work and prepare this manuscript (Tong, 2007).

Thematic analysis is an established and useful method for organising and observing patterns in qualitative data, in this case the single focus group transcript. In line with good practice use of the method (Braun and Clarke, 2006; Ritchie and Lewis, 2010) the transcript was repeatedly read through and key themes (a priori and emergent) identified, coded for, grouped together and interconnections between themes examined (Pope et al., 2006).

Results

Interviewers described a number of barriers to access for South Asian people with ESKF. These related either the experience of end of life care reported by patients or the interview process itself.

Key theme 1: Access

The lack of information that the study participant appeared to have about the interview led interviewers to conclude that unless there had been members of the kidney team with language skills to speak directly to the patient, non-English speakers understood very little about the purpose of the interview.

'...one of the patients I contacted directly, I think with the other two I went through one of the health workers.... I think that that helped because I had a discussion with (name of health worker) first, she then had a discussion with the two patients. I then had a discussion with two patients and then they had further discussion with (name of health worker). Yeah and I felt that actually it was quite smooth and even though it might sound long winded actually it was quite smooth and they were accepting of that because they were already being told about it, then (name of health worker) reinforced it.. (Interviewer 1)

Where the person did not speak English the study participant relied on family members for translation. The latter had a gate keeping role in making contact and setting up of the interview and in reporting on the care received during the interview in many cases.

'It was the son's number that was given to me to contact, it wasn't the family's number or the home number..... The parent did not know and this went on for several weeks and because I

kept thinking O.K I will give you another week. Then there was a family do and then we had to wait after that.....It was really, really difficult to get the son to commit and the second chap, same thing happened, it was a son again...and when I go there, the patient was absolutely happy, was not a problem at all. The family caused a lot of toing and froing about actually committing to be talking about this topic.’ (Interviewer 2)

Sub-theme: Intergenerational barriers

Interviewers acknowledged the family’s desire to protect their relative from any upset which might arise from discussing end of life care in an interview. Interviewers thought this highlighted a perceived intergenerational and cultural difference between an older South Asian, who may be a first generation migrant, and the next generation who had grown up with more westernised ideas and values about end of life care. Furthermore they felt this contributed to the misconception that older South Asian people would be sensitive about discussing end of life.

‘ I think personally, I might be wrong but I think Asians are not as sensitive to this area as other communities might be....’ (Interviewer 3)

‘...sorry but they (the patient) might not be, but the families are. Aren’t they? That’s the thing for me. It was almost like bringing the name of death up would sort of tempt fate for it to be sooner or whatever you may wish.....the younger generation is being influenced by living in a western cultures whereas for the older Asians death is part of life.’ (Interviewer 2)

Focus group participants reported that despite some patients having minimal prior understanding about the research, once the interviewer had gone through the research

information again and informed consent had been taken, patients were willing to talk about issues relating to end of life. Interviewers attributed this to the attitude that age and ageing in South Asian cultures is a process accompanied by respect as well as a decline in health. Therefore a life limiting condition such as ESKF is handled with resignation and acceptance..

'A lot of people were quite happy to talk and I was quite nervous about well, I know we had sensitivity training about end of life and I thought it might make them quite uncomfortable or I was scared to talk to them about it a little bit, but they were quite forthcoming in their story, and their acceptance of the stage that they were at and things like that, so that wasn't as difficult as I thought it would be.' (Interviewer 4)

'...she had accepted, "oh it's a cycle we all go through. It is not like washing machine that goes out after seven years, (but) it is the same way our body has to go" and she was quite positive in a way..' (Interviewer 5)

Key theme 2: Talking about end of life

Interviewers described how patients were less inclined to talk about their own feelings towards end of life than to talk about their care in more indirect terms. Feedback from an interview conducted with a patient whilst they were undergoing dialysis illustrated this and highlighted the difficulty for interviewers in approaching an issue which the interviewee may not have discussed with anyone before.

'She was very very unwell. She had not accepted that she was going to stop any treatment whatsoever and it was very difficult (for the interviewer) to say to her "so what you think,

what are you thinking is going to happen next?” because she was not going to go, she didn’t want to go there because she was going to carry on.’ (Interviewer 6)

Researchers suggested that even where there was acceptance of the prognosis patients did not necessarily wish to talk about it.

Commented [A2]: Should this come under this theme – or is this a standalone discussion related to barriers perceived by the interviewers?

‘...so even though there was an acceptance of dealing with that issue I don’t think they wanted to discuss.... But I don’t think they have felt comfortable enough about talking about it because that may have made it more, I don’t know, I am just saying it make it even more final for them.’ (Interviewer 1)

Recording the interview and conducting a single interview were acknowledged as limitations to achieving a comprehensive and authentic account of patient experience. Interviewers suggested the presence of recording equipment and the limited time over which to build rapport with the interviewee could inhibit the degree to which interviewees felt at ease in discussing personal feelings.

Sub-theme: Lack of awareness of end of life care

Patient interviewees, however, had not been familiar with the term ‘end of life care’ and interviewers had found it a difficult concept to translate. The lack of awareness of end of life care came with a lack of expectation that anything more could be provided for them by their care providers. Interviewers thought that this was likely to be a reflection of poor access to information due to communication barriers in healthcare encounters such as translation and lack of time.

'One thing that came out a lot for me, and all of that, was the lack of information that each of those patients had about what end of life care was. What services actually were available to them.....and they were very resigned to "well we get what we need" but I don't think that they actually knew about all the services that were available to them.... in at least one of those three.....that patient wasn't in a position to get the information even if he wanted because of barriers like language barriers, for example communication barriers.'

(Interviewer 1)

Key theme 3: Interview training and preparation

Interviewers suggested that for some of the patient participants who did not speak English the research interview may have been the first time that they had communicated directly about their care and not through a formal or informal interpreter. In this scenario, interviewers felt they had been prepared by the project specific training and that their interviewing skills and experience helped them to manage the discussion carefully and with empathy.

*'...it's like, it depends how you format the question to them and I think you have just have to play it by ear, assess the situation....I think I was feeling, because the training really intense and the way the training was coming out... oh my God how are you going to?I was drained by the end of the day, I was like how I was going to do this? It is very sensitive. But the one (interview) that I did, I did not find it that difficult to be honest because I think I just kind of changed the question a little bit and said, you know, "how do you feel?"...'.
(Interviewer 3)*

Despite being identified as receiving or soon to be receiving end of life care, the majority of patients appeared to be in better health and easier to initiate conversation with about their

care than interviewers had anticipated. Without outward signs and symptoms of rapid decline, interviewers felt that it might be easier for patients to be accepting of the end of life phase in a fatalistic way and not talk about it. With this mind set interviewers suggested that patients and their families may be less inclined to access help to improve their situation.

'The older they get, they get quite fatalistic. That isn't just the Asian thing, but families then have an issue, especially if they look well. You know like the lady, you have sort of..... if they look fit and well and their disease is not sort of showing symptoms outwardly, the family find it really hard to accept, therefore they will be quite defensive if you are implying that they need to access to end of life things.' (Interviewer 2)

Sub-theme: Better understanding of end of life context

As discussions with patients touched on personal issues as well as highlighting gaps in information, interviewers felt it was important that they were equipped both with better knowledge of the context of ESRF and end of life kidney care as well as information which would signpost participants to relevant services to deal with any queries raised. This was more the case for interviewers who did not have a healthcare background, but all interviewers agreed that they had needed to draw on empathic interviewing skills and careful management of the discussion with the interviewee and family members who were often present.

'... I think of it from two aspects actually, I think from two sides...firstly, I had confidence in my ability to carry out a one to one interview with somebody, but because of the nature of the topic I kind of half felt unequipped because I think you didn't know what was going to come up in the interview.....I felt equipped enough to do the interview but I just felt a little bit unequipped in terms of medical background, just in case people started asking medical

questions and yeah there is a way that you deflect that and get around that but that was always in my mind.’ (Interviewer 1)

Key theme 4: Role of the research interview

Where patients had sought counselling and found it unhelpful or where requests for follow up practical support had not materialised, interviewers felt there was a need for research such as this to feedback directly to services on an individual basis in order to promote positive and timely outcomes if at all possible.

‘and it would be useful if we felt a particular person would benefit that we could lead (them) back to the clinicians and say “you know we I don’t know how clinicians would feel about it because you know we aren’t strictly healthcare staff” it will be good to link back to the service provision.’ (Interviewer 2)

The group raised the issue of the researcher role with respect to the ethics of providing additional information and signposting the interviewee to information sources in the context of the research and patient care. Interviewers also expressed frustration of not being able to respond to patient concerns in an active.

Commented [A3]: Incomplete.

‘one thing I did find difficult was when they would start talking about their personal issues with their families, half of me wanted to give them some advice on that and I was kept saying to myself “you can’t do that”I felt I really want to see these people again but I know that it’s not going to happen in that regard. So I think it may be therapeutic for some of them to get some of that out of their system but I felt that they were not going to get any assistance in how to deal with some of those issues.’ (Interviewer 1)

Sub-theme: Therapeutic role

There was consensus that, in the context of end of life care for South Asian patients with ESRF, research interviews could potentially fulfil a therapeutic role. It was suggested that this may have been the first opportunity for the person to communicate directly in their preferred language about how they were feeling about their situation, care needs and experience. Similarly interviewers picked up on family member's needs for discussion and counselling, separate to the patient, as well as their own needs as interviewers to debrief soon after the interview by recording their thoughts and comments through a 1:1 with another researcher or in a group.

'...a definite way for them (the patient) to be able to express their feelings, you know (in a) safe environment knowing it could be a one to one scenario or that they can actually sort of say as they really felt and not "I have to put on that brave face".' (Interviewer 7)

'...especially the ones if they couldn't talk to their families. One of mine said, you know what, when they went out of the room for something, one of our patients said "you know you can't really talk to the...you know because they hear and then they get worried"... and the converse for families too, when on the phone, when you are arranging the interviews on even afterwards, the families would talk to about the things they thought the parent, or you know, needed...almost saying "we can't really say it in front of them".' (Interviewer 2)

Patients handling the burden of care alone in order to protect family members and to prevent conflict within the family as a result treatment decisions, were given as examples of where patient experience could be improved. Better access for both the patient and their family to

discuss their concerns directly with a counsellor or similar was identified as a potential solution.

'...one of the things I remember about thinking is the counselling issues for the extended family because he (the patient) had resigned himself you know, he was actually quite clear that as far as he was concerned this was the best option for him and the best option that could, you know, come out of the current situation, but the family were not at all happyI think there is a lot of work around the families that does need to be done.' (Interviewer 7)

Key theme 5: Ethical considerations

Interviewers highlighted some of the ethical dimensions of their observations. These related mainly to the idea that there were missed opportunities for the research to benefit patients.

Sub-theme: Giving something back

That participation in the study was not expected to lead to any benefit for participants themselves was a source of discomfort for some of the interviewers as was the idea that without any follow up it felt as if the research 'took' from participants without 'giving' anything in return.

'Doesn't matter what you want, we get what we wanted, we are going to be off now...I don't think that's kind of fair for them from where they are coming from. If you could, were allowed and if the ethical process, you know, allows, we could go to this department for that, because they (the patients) probably haven't got any means to ask somebody else sometimes. They don't, because you develop a trust relationship doing these interviews because they

wouldn't be forthcoming with information if they did not feel comfortable with you. So I think that's quite important.' (Interviewer 3)

Developing trust with participants through the process of arranging and conducting the interview was seen by interviewers as a positive aspect of the research for patients. However, interviewers voiced concerns about the perceived power dynamic between patient and medical team with which the researchers were associated. This could limit opportunities for the research to benefit the patients if, out of deference for medical profession, patients felt they should present their experiences in a good light. Interviewers thought this was linked to how well-informed participants were about the research beforehand and feelings of obligation to participate, altruism and hospitality towards the researchers. A greater understanding of the ethical considerations and constraints in relation to the interviews, some interviewers felt, would have improved their experience of the process.

'I would personally like the ethics bit to come in to it more like, you know, how far we can go as interviewers? Definitely, and that would make me become more comfortable and it would be a better interview because I could give back as well.' (Interviewer 3)

Discussion

The limitations of previous research studies which have excluded non-English speakers and the need for the inclusion of 'harder to reach' groups in end of life research have been identified by other researchers (Burden et al, 1992; Goodman et al, 2012; Vickers et al, 2012). Older people, people from ethnic minority groups and people at end of life come into the 'harder to reach' category despite making up a significant proportion of the population of patients with ESKF in the UK (Castledine et al, 2014). Including people with a South Asian ethnic background and having a bilingual interview team which enabled participation by non-English speakers has gone some way to fill a gap in end of life research and specifically in kidney care.

What the research process tells us about access

Interviewer reflections on the research process revealed important observations about access to end of life care for kidney patients who had a South Asian ethnic background. This was in line with an action research approach to reflect on research implementation to generate theory and inform service improvements (Hart and Bond, 1995) and the resulting observations highlighted issues of relevance to both research and practice.

Although access to care and participation in research are two different things, both are underpinned by meaningful information and communication in written or spoken form. Achieving access to participation by patients in the study itself was not as difficult as the interviewers had anticipated and was helped where there had been good communication between the patient and clinical team at recruitment, or once contact had been made by a member of the bilingual interview team.

However, the data from this focus group also suggested that in several cases gatekeeping by family members was a barrier in gaining access to patients willing to participate in the research. Where family members were involved in setting up the interviews, interviewers suggested there were intergenerational barriers to discussing end of life, with both patient and family member trying to protect the other because of perceived sensitivities. The idea that hope is not diminished through discussion of end of life with kidney patients is something that other researchers have explored (Davison and Simpson, 2006), however, gate-keeping by South Asian families has been found to be a barrier to access to palliative care services in patients with a range of life limiting conditions (Worth et al, 2009).

The barriers to discussing of end of life care with South Asian patients

Interviewers reported that all of the patients recruited had been willing to be interviewed about their care but that there appeared to be a general lack of awareness amongst patients interviewed of what end of life care was. There seemed to be acceptance of their condition but in some cases avoidance of discussing end of life and dying any further. Whether this related to the choice of care pathway (many had chosen conservative care) and their stage along it (early on), or was cultural, it was not possible to say from these observations, but interviewers thought that all patients would have benefited from more information and communication about end stage kidney care because of this lack of awareness.

The lack of awareness reported above may relate to intergenerational and language barriers and reflect limited opportunities in practice for direct communication between patient and clinician if family members are always present for translation purposes as well as other reasons. Despite the acknowledgment that using family members to translate and communicate can be problematic and not good practice in many situations (Villareuel et L,

1999), translation resources are not always available and moreover end of life care includes the patient and their family (Department of Health, 2006; National Council for Palliative Care, 2006).

Lack of awareness and communication in contributing to reduced access to palliative care in black and minority ethnic groups (BAME) has been highlighted in a wider review (Calanzani et al, 2013) as has the need for a more nuanced and individualised understanding of the influences of ethnicity and culture on access to end of life care (Koffman, 2014). The interviewer observations of patient experience in the kidney setting concur with these general findings suggesting that kidney patients were willing to discuss end of life care but may not have had the opportunity to do so previously. The interview schedule with prompts allowed interviewers to adapt their questioning style to each interviewee and the interviewers were experienced in working in a culturally sensitive way.

A desire to discuss advance care planning has been identified in the kidney population in Canada (Davison, 2010) and the National Service Framework for Renal Services, kidney care framework for implementation and End of Life Strategy in the UK emphasise timely identification of supportive and palliative care needs and sensitive communication with patients (Department of Health, 2005, NHS Kidney Care, 2009, Department of Health, 2008). However, there can be ethical challenges for clinicians discussing end of life care with patients and families who have different cultural backgrounds in the context of the UK health system, and good communications skills are an essential part in ensuring equitable access (De Pentheny O'Kelly et al, 2011).

Conducting research with patients about end of life care similarly requires careful and sensitive communication by interviewers particularly, as we have seen here, where there may be a lack of awareness, information and prior communication. Interviewers felt that their training in sensitive interviewing for the project had equipped them well but that the research raised some ethical issues for them as interviewers in relation to this group of patients.

Commented [A4]: This is also another important aspect of this process that should be elaborated upon. Training for the interviewers has been noted on several occasions but there is no background on what this actually entailed.

Developing the therapeutic potential of research interviews

The lack of awareness of end of life care and communication barriers meant the research interview may have been the first opportunity that some patients had had to talk about their experiences directly in their preferred language. In this case, interviewers who had a non-healthcare background felt they needed to be better equipped to provide information about end of life kidney care and also have a means of providing feedback if they found there were unresolved issues for the clinical team to take action on. Secondly, if there was an unmet need for the patient to talk about their end of life care and the research interview was more integrated with patient care, it could be a vehicle for information and support and thereby provide a potentially therapeutic role.

These points also relate to observations from patient data which found that where patients had language specific discussions with their clinical team these had been reported as a positive aspect of their care whereas a patient who had sought counselling reported that this had not met their needs or those of their family (Wilkinson, 2014). The interviewer reported data presented here found there were participants to whom the interviewers would have liked to have been able to offer advice and support during the course of the interview. This, interviewers felt, represented a missed opportunity as well as an ethical point of consideration for those planning and delivering research. The situation in which participants gave but did

Commented [A5]: Please revise this sentence – there are many important aspects highlighted that should be expanded upon.

not receive anything back interviews thought could be at odds with the ethos to maximise quality of life in an end of life timeframe.

Other researchers addressing sensitive topics including end of life care (Seymour et al, 2005) and interviews with bereaved parents (Sque, 2000), provide guidance on some of these issues. This study was implemented sensitively by interviewers following training and according to an approved ethical approach which reflected the exploratory nature of the research rather than its clinical application. Observations analysed here take ideas of beneficence further to suggest that future exploratory end of life research develops the potential therapeutic role to benefit patient participants.

Commented [A6]: Please dissect these thoughts. There are multiple run-on sentences in this manuscript.

Although interviewers reported that the people they interviewed had identified them as part of their care team, implementation of the patient interviews by predominantly 'lay' (non-clinical) bilingual interviewers most of whom had a South Asian background themselves, afforded the research and the interview process both cultural understanding and a degree of neutrality with which to ask about end of life care experiences. The research itself was limited by including just one interview lasting up to one hour with each patient. As such, interviewers needed to have good communication skills in order to build rapport with interviewees in a short space of time.

The advantages of using 'lay' interviewers in research are not only for their language skills but because they offer a broader cultural perspective and capacity to contextualise issues from a cultural point of view (Mulder & Dwyer, 2014). Interviewer reflections on conducting end of life care research illustrated where access to all aspects of end of life care as described in UK end of life policy was not achieved with this group of patients with ESRF.

Whether this could be attributed to many of the patients being early in a conservative pathway of care is not clear, but a future study which takes a longitudinal approach and comprises more than one interview would contribute further to our understanding.

Conclusion

By focussing on interviews conducted with South Asian people with ESKF, we have identified important points to take forward for research into inequalities in end of life care.

Our analysis indicates that exploratory bilingual research interviews in the kidney context are able to contribute to the knowledge base in end of life research, identify where patient awareness is lacking and could have a therapeutic role with appropriate training, support and ethical issues addressed. A closer and more direct relationship between patient experience research and clinical practice which facilitates communication may be one way to improve patient access to all aspects of care in a timely way for South Asian kidney patients at end of life.

Ethical approval

This research study was approved by the National Research Ethics Service (Essex 1 Research Ethics Committee, ref no: 09/H0301/62) prior to commencement.

References

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology Qualitative Research in Psychology 3; 2; 77-101 <http://dx.doi.org/10.1191/1478088706qp063oa>

Burden, A., McNally, P. & Feehally, J. 1992 Increased incidence of end stage kidney failure secondary to diabetes mellitus in Asian ethnic groups in the United Kingdom. *Diabetic Medicine* 9: 641-645

Calanzani N, Koffman J and Higginson IJ (2013). Palliative and end of life care for black, Asian and minority ethnic groups in the UK: demographic profile and the current state of palliative and end of life care provision. Public Health England, King's College London and Marie Curie Cancer Care.

Castledine C, Davenport A, Dawnay A, Farrington K, Fogarty D, Kumwenda M, MacPhee I, Ramanan R, Roderick P, Sinha MD, Williams AJ 2014 17th Annual Report of the Kidney Association Nephron Clinical Practice 2015 129 (supp11)
<https://www.kidneyreg.org/reports/2014-seventeenth-annual-report/>

Davison, S. 2010 End of life care preferences and needs: perceptions of patients with chronic kidney disease *Clinical Journal American Society Nephrology* 5;2;195-204

Davison, S. and Simpson, C. 2006 Hope and advance care planning in patients with end stage kidney disease: qualitative interview study *British Medical Journal* doi: 10.1136/bmj.38965.55

Da Silva Gane, M. and Farrington, K. 2014 Supportive care in advanced kidney disease: Patient attitudes and expectations *Journal of Renal Care* 40; 1; 30-35

Department of Health (2005) National Service Framework for Renal Services - Part Two: Chronic kidney disease acute renal failure and end of life care. Department of Health, London.

Department of Health. End of Life Care Strategy 2008.

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf

De Pentheny O'Kelly, C., Urch, C. and Brown, E. 2011 The impact of culture and religion on truth telling at the end of life *Nephrology Dialysis and Transplantation* 26; 3838-3842

Finch, H. and Lewis, J. 2010 Focus Groups in Ritchie, J. and Lewis, J. (Eds) *Qualitative research practice: a guide for social science students and researchers* Sage Publications Ltd ISBN 978-0-7619-7110-8

Gill, P. and Lloyd, C. 2009 Participation in research In: *Diabetes UK and South Asian Health Foundation recommendations on diabetes research priorities for British South Asians* Eds: Kunti, K., Kumar, S. and Brodie, J. ISBN: 978-1-899288-88-5
https://www.diabetes.org.uk/upload/Reports/South_Asian_report.pdf

Goodman, C., Froggatt, K. and Mathie, E. 2012 End of life Care *Methods Review* School of Social Care Research ISBN: 978-0-85328-444-4

Gulliford, M, Figueroa-Munoz, J, Morgan, M, Hughes, D, Gibson, B, Beech, R & Hudson, M
2002, 'What does 'access to health care' mean?' *Journal of Health Services Research and
Policy*, vol 7, no. 3, pp. 186 - 188., [10.1258/135581902760082517](https://doi.org/10.1258/135581902760082517)

Hart, E. and Bond, M. 1995 Action research for health and social care: a guide to practice
Open University Press ISBN 0-335-19262-9

Kane, P., Vinen, K. and Murtagh, F. 2013 Palliative care for advanced renal disease: A
summary of the evidence and future direction. *Palliative Medicine* 0; 0; 1-5

Kitzinger, J. 2006 Focus groups Chapter 3 in Pope, C. and Mays, N. Qualitative research in
health care 3rd Edition BMJ Books Blackwell Publishing Ltd ISBN: 978-1-4051-3512-2

Koffman, J. 2014 Servicing multi-cultural needs at the end of life *Journal of Kidney Care* 40
(Suppl 1) 6-15

Morton, R.L., Tong, A., Howard, K., Snelling, P. and Webster, A.C. 2010. The views of
patients and carers in treatment decision making for chronic kidney disease: systematic
review and thematic synthesis of qualitative studies. *British Medical Journal* ONLINE
FIRST

Mulder, S. and O'Dwyer, M. 2014 The first language advantage: Working with bilingual
research assistants AMES Research and Policy Unit

http://www.ames.net.au/files/file/Research/First%20language%20advantage%20paper_May%202014.pdf

National council for Palliative Care 2006 End of life care strategy
http://www.ncpc.org.uk/sites/default/files/NCPC_EoLC_Submission.pdf

NHS Kidney Care. National End of Life Care Programme. 2009. End of Life Care in Advanced Kidney Disease: A Framework for Implementation.

<http://www.endoflifecareforadults.nhs.uk/publications/eolcadvancedkidneydisease>

Randhawa, G., 2012 Kidney health and transplantation: a focus on ethnicity. *Journal of Kidney Care* pp.109-114

Seymour, J., Payne, S. and Reid, D. 2005 Ethical and methodological issues in palliative care studies: The experiences of a research group *Journal of Research in Nursing* 10; 2; 169-188

Sque M. (2000) Researching the bereaved: an investigator's experience. *Nursing Ethics*, 7; 1; 23-34

Tong, A., Sainsbury, P. and Craig, Jonathan Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups *International Journal for Quality in Health Care* 19;6;349-357

Vickers, T., Craig, G. and Atkin, K. 2012 Research with black and minority ethnic people using social care services, *Methods Review* School of Social Care Research ISBN: 978-0-85328-445-1

Villarruel, A., Portillo, C. and Kane, P. 1999 Communicating with limiting English proficiency persons: Implications for Nursing Practice *Nursing Outlook* 37; 6; 262-270

Wilkinson, E., Randhawa, G., Brown, E., Da Silva Gane, M., Stoves, J., Warwick, G., Akhtar, T., Magee, R., Sharman, S. & Farrington, K. (2014) Communication as Care: an emerging issue from an exploratory study of kidney end of life care for ethnic minorities in the UK. *Journal of Kidney Care* 40; issueS1; 23-29; doi: 10.1111/jorc.12084

Worth, A., Irshad, T., Bhopal, R., Brown, D., Lawton, J., Grant E., Murray, S., Kendall, M., Adam, J. Gardee, R. and Sheikh, A. 2009 Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study *British Medical Journal* doi: 10.1136/bmj.b.183

Table 1: Interviewer languages

Interviewer ID	Language
Interviewer 1	Pahari
Interviewer 2	Punjabi
Interviewer 3	Pahari
Interviewer 4	Gujarati & Hindi
Interviewer 5	Gujarati
Interviewer 6	English
Interviewer 7	Punjabi
Interviewer 8 (not at focus gp)	Bengali
Interviewer 9 (not at focus gp)	Punjabi

DRAFT